

they seize power plants and the government becomes your local electric utility. It would be the most inefficient operation in the history of our government. Do not let them do it. You cannot get something for nothing out of this government. If it is the government running it, you usually pay a higher price than if you as a community can have the private sector with checks and balances. I have spoken primarily about energy, about water.

Mr. Speaker, one last shot on water and then I am done. That is keep in mind in the East and West of this Nation, there are differences in water and differences in public lands. I would urge all of my colleagues in the East and all of their constituents in the East to please take the time before signing on a petition to take on Lake Powell or kick people off public lands, take a look at both sides of the story. If you take a look historically, politically, environmentally at both sides of the story, I think you will have a better understanding of what I have said tonight and a much deeper appreciation for our message from the West.

HIV/AIDS

The SPEAKER pro tempore (Mr. REHBERG). Under the Speaker's announced policy of January 3, 2001, the gentlewoman from North Carolina (Mrs. CLAYTON) is recognized for 60 minutes as the designee of the minority leader.

Mrs. CLAYTON. Mr. Speaker, oftentimes we act on perceptions rather than reality, and when we discuss HIV and AIDS, indeed that has been one based on perception. Oftentimes we have felt, those of us who live in the rural South, have felt that AIDS was an issue of the North. Those of us who lived in small towns felt it was an issue of the big cities. Heterosexual persons thought this was only an issue for gays or that it was indeed white male gays. What we are finding is that those perceptions were ill-founded, and that the disease has affected all phases of the United States, particularly the South.

HIV/AIDS is becoming more prevalent in rural areas and in the South. AIDS cases in rural areas represent only about 5 percent of all reported HIV cases in 1995. Only 5 percent. However, the pattern of HIV infection suggests that the epidemic is spreading in rural areas throughout the United States. HIV in the rural South is growing at one of the fastest rates in the Nation. The Southeast as a whole has the highest number of those infected. The southern region of the United States accounts for the largest proportion; that is, 34 percent, 34 percent of 641,886 AIDS cases. The latest figures we have is for 1997, and 54 percent of the 56,689 cases are among persons residing in rural areas.

However, according to a Boston Globe article, which I include for the RECORD, according to this article it references that in six Southern States, in-

cluding my State, North Carolina, and South Carolina, Georgia, Alabama, and Mississippi as well as Louisiana, 70 percent of those with HIV are African American, and 25 percent are women, according to a Duke University study.

But more importantly, here is what it says. Both of these figures are higher than the national average, but few are saying anything about it, keeping the disease nearly invisible as it spreads. It is a deadly, silent disease. It is the silence that worries many of the AIDS activists who are fearful that as the silence continues, the government will not know that they have a problem.

The text of the article is as follows:

[From the Boston Globe, June 1, 2001]

IN THE SOUTH, DEADLY SILENCE

SHAME AND FEAR CONTRIBUTE TO RAPID SPREAD OF HIV IN RURAL AREAS

(By John Donnelly)

SCOTLAND NECK, NC.—In the short, grim history of AIDS, this rural town surrounded by cotton and tobacco fields would probably go unnoticed. The virus hasn't killed people here in great numbers, as it has in Africa, nor has it devastated a whole sector of the population, as it did to gay men in the cities of America in the 1980s.

But as observers reflect on the two decades since the first public mention of a disease that was later named Acquired Immune Deficiency Syndrome, the overarching reality is that the virus has stealthily managed to infect roughly 60 million people all over the world, including here on Roanoke Street, inside the four-room house of the Davis family, in the person of one Jeff Davis.

And that remains, largely, a secret here.

"I keep it pretty quiet," said Davis, 26, his skinny 6-foot-3 frame sprawled out over a worn-out sofa as his mother hovered nearby. "I'm not sure people would like being around people like me. If they find out I'm HIV-positive and their reaction was bad, I don't think I could take it." HIV in the rural South is growing at one of the fastest rates in the nation. The Southeast, as a whole, has the highest numbers of those infected. In six Southern states—North Carolina, South Carolina, Georgia, Alabama, Mississippi, and Louisiana—70 percent of those with HIV are African-American and 25 percent are women, a Duke University study found. Both figures are higher than national averages.

But few say anything, keeping the disease nearly invisible as it spreads. It is this silence that worries many AIDS activists, who are fearful that as the US government grapples with the out-of-control pandemic in parts of sub-Saharan Africa, it will neglect the increasingly costly programs to treat infected citizens at home. In at least a dozen states, there are waiting lists of people infected with HIV who want to get the drugs.

At home, the Bush administration's initial position has been to put a lid on treatment funds. It has proposed no increase next year for the \$1.8 billion Ryan White Care Act, which pays for AIDS cocktails for Americans not covered by Medicaid or other insurance programs. Abroad, the administration has put \$200 million in additional HIV money into a newly created Global AIDS and Health Fund, a sum belittled by many advocates as a trivial response to a problem that Secretary of State Colin L. Powell calls a war without equal. "It's our responsibility as a world leader to fight AIDS at home and around the world," said Ernest C. Hopkins, director of federal affairs for the San Francisco AIDS Foundation. "Furthermore, the crime of someone in rural North Carolina

not getting treatment is far more egregious than the reality of that happening in sub-Saharan Africa, where countries spend a few dollars per capita on health care. This is an incredibly resourced nation, and yet there are people here who are basically being written off."

In the past 20 years, AIDS has killed 438,795 people in America, 23 million worldwide. In the United States, an estimated 1 million people are now infected with HIV or have full-blown AIDS, but only about a third of them are receiving treatment. The federal Centers for Disease Control and Prevention estimates that another third of a million have been diagnosed but either aren't medically eligible for treatment or can't pay for it, while the remaining third don't know they are infected or refuse to be tested.

AIDS has remained largely an urban epidemic in America, but infection rates have been rising rapidly in rural areas. Interstate highways act like spigots that flush the disease deep into the back country. Sex workers set up shop along the highways. And from rural Southern towns, as elsewhere, people like Davis travel to neon-bedecked bars or strip joints located near interstate highway ramps, pay for sex, and bring the virus back home. Some, like Duke public health specialist Kathryn Whetten-Goldstein, "see echoes of Africa in HIV in the South," because of the barriers to care as well as the way the virus is increasingly transmitted through heterosexual contact. In the rural South, about 45 percent of women with HIV were infected by having sex with infected men, compared with 15 percent nationally; in Africa, as much as 80 percent of the transmission is heterosexual.

"When you think about the epidemics being similar," said CDC epidemiologist Amy Lansky, "in the rural areas, particularly in the South, there is a lot more transmission occurring through heterosexual contact than you see as a nation as a whole."

It is an outrage, in Whetten-Goldstein's thinking, because heterosexual transmission carries far less of a stigma than homosexual transmission. And yet, few talk about it, which she believes is rooted in racism.

"If the rates of heterosexual transmission were as high in middle-class white women and men as they are among African-American men and women, policymakers and power holders would be terrified and acting quickly," she said.

But Whetten-Goldstein believes the similarities between the rural South and Africa go deeper than the mode of transmission.

"There's a great stigma here attached to the disease, a sense of fatalism that it doesn't matter what they do and the great distances people have to travel to see a doctor," she said.

In both Africa and the rural South, a lack of education about how the virus is spread has allowed it to flourish. In North Carolina, for instance, state law forbids schools to teach that condoms can help prevent the spread of AIDS; teachers can only talk about abstinence.

And like many places in Africa, the stigma of living with HIV/AIDS is reinforced by attitudes of some fundamentalist Christians. Here, many fervently believe that God is punishing those with AIDS for their sins.

One woman in rural North Carolina who would be identified only as Sylvia said she travels 180 miles to see an AIDS doctor three times a month, even though there is an AIDS specialist 40 miles away. "If you go to the local doctor, everyone knows you have HIV," said Sylvia, a local PTA president and a Cub Scout den mother.

"It's a modern-day leprosy here," said Dr. Mario G. Fiorilli, the only AIDS doctor in Halifax County in northeastern North Carolina. The great differences between the

United States and Africa, of course, are that antiretroviral AIDS drugs are widely available here. But availability of drugs does not always guarantee access, and flat-funding of the Ryan White Care Act would mean that many newly infected Americans will be denied drugs, advocates say.

In interviews with several dozen AIDS caseworkers and patients in rural areas of North Carolina, many said that potentially thousands of people refuse to get tested for HIV, while others fail to adhere to the daily regimen of pills for a variety of reasons, including painful side effects. "I have friends—and I don't agree with them—who are sleeping around with it," said a man who asked to be identified only as J-Ray, a now-celibate drag queen who adheres to the strict drug regimen. "They're just spreading it. That's what's going on here. You have people who are either too scared to get tested, or find they have it and basically don't care at all. They're just angry."

Like many interviewed, J-Ray did tell family members he had the disease. "My mother hugged me," he said. "My father looked at me, and said, 'Do you have life insurance?'"

Beamon Vann's family reacted by kicking him out of the house. For 14 months, with no independent source of income, he lived in a leaky aluminum box 6 feet high and 8 feet wide behind his family's three-bedroom house, allowed in only twice a week for showers. His mother handed him meals out the back door. She gave him a metal bucket for a toilet.

"It was because of her ignorance, her faith, her feeling that the disease was God's punishment," said Vann, 41, in his new three-room home, staring at a game of solitaire, three aces showing.

Vann, who is gay, began to weep. "The first words out of my mother's mouth were, 'I told you God would get you one day for what you've been doing.'" Vann's caseworker is Terry Mardis, who is retired from the Army after 26 years in the special forces. He carried out secret missions in Vietnam, Nicaragua, and Panama. It's natural for him to use war metaphors in describing his work with AIDS patients.

"Are we making a dent? No," said Mardis, 53, who works for the Tri County Community Health Center in Newton Grove. "I doubt it very seriously. People are afraid to get tested."

On the road one day recently, in between visits to clients dozens of miles apart, Mardis said poverty often interferes with treatment. "I have one woman whose daughter takes money from her. She has Social Security, which pays her bills and her phone, barely. Then family members run up \$600, \$700 in phone bills," Mardis said.

"We're concerned about her" staying on her medication, he added. "You're fighting a war here—on several fronts," Mardis said. "You have families working against you. You've got communities working against you. I go and ask some businesses for donations to help those with AIDS, and they look at you like you're strange. Their idea of a crisis is the Red Cross helping you if you're burned out, not if you have AIDS."

In Halifax County, HIV case manager Kathy W. Knight has worked hard to get African-American ministers to fight the stigma of the disease. "People won't change their attitudes until it comes from the pulpit. If it doesn't come from the pulpit, it ain't the truth. If ministers think they can get it from eating at McDonald's, which is what one told us, then we're still going to have trouble here."

Few say a kind word. One who won't is Bishop Moses Williams Jr., pastor of the Love of God Church of Christ. "These dis-

eases come upon people because they are not obeying the work of God," he said waiting in line at a Roanoke Rapids pharmacy check-out.

Jeff Davis, who believes he contracted HIV one night when he had sex with a stripper in Roanoke Rapids, just off interstate 95, is responding well to his combination of antiretroviral drugs. His weight rebounded to 164 pounds, from 142, but he is wary because his health has gone upon and down before. "There was a time when Jeff was falling away to nothing," said his father, Perry Lee Davis, 68. "I felt like then just as I did when he was a small child. We all love him. How would I feel as a father if I turned my back on him because he has HIV? I would be less than a father."

Jeff Davis, sitting on his father's bed, listened to him. "I read my Bible every day," he said softly. "I'm back in church. It's made me better. I think everyone in there knows about me. But no one says anything."

Mr. Speaker, tomorrow we will be offering an amendment to make sure that sufficient food goes to those persons in Africa who are suffering from the AIDS pandemic and their children and families who are taking care of them.

But if we do not recognize here in the United States, and particularly in the South, that we have this disease, it is unlikely we will get additional funds. In fact, when we look at the budget, the Ryan White Care Act, which pays for AIDS cocktails, is maintained about where it was.

The Globe article further says that in the rural South, about 45 percent of women with HIV/AIDS are infected by having sex with infected men, again breaking one of the perceptions we have that heterosexual persons will not be subject to it. But, indeed, the infection rate is 15 percent above what it is nationally. The spread of AIDS in Africa is being spread through heterosexual transmission of the disease rather than homosexual. In fact, women and children are the ones who are most infected.

Again, one doctor in this area, and they are referencing North Carolina and referencing Halifax County, which is in my district, this doctor says, Dr. Fiorilli, the only AIDS doctor in Halifax County, "This is like a modern day leprosy, no one wants to claim or talk about it."

Mr. Speaker, the big difference between the United States and Africa are that the medications we have are more available here, but availability of drugs does not guarantee access because there are people failing to take the test to find out whether they are eligible, and then there are people who are failing to follow their prescription.

In interviews many said that potentially thousands of people refuse to get tested for HIV, and one person states she travels 180 miles to get treated twice a month when she could travel 40 miles and be treated, but everyone knows her in her area. This person is president of the PTA and very active as a leader, and so the culture of the area does not allow her to seek out medical care, and in some instances not even to

tell their own family members. We have a problem in the Southeast and in those six States.

The number of new AIDS cases in the United States began to decline in the mid-1990s, but actually the rate went up in the South. While everybody else was kind of dealing with the problem and acknowledging that we had a problem, actually it went up. Particularly we find this happening in the South among black women as well as with children. It is true there are still more males than females, but the growth rate for women is extremely high in that area.

Mr. Speaker, from 1981 to 1999, 26,522 black women developed AIDS in 11 States of the former Confederacy. In Mississippi and in North Carolina, statistics show that more black women than white men have contracted HIV.

By region of the United States, AIDS incidence increased in all regions from 1994, with the most dramatic increases in the South. In 1996, however, AIDS incidence dropped in the Midwest, dropped in the West and the Northeast, and just began to level off a little bit in the South.

Now, again back to North Carolina, the HIV epidemic continues in North Carolina. Rates of infection continue to grow among adolescents and among women, with heterosexual contact as their primary mode of transmission. The minority population is disproportionately affected by the AIDS epidemic in all risk groups. The geographic distribution of cases for HIV/AIDS and bacterial STDs indicate the high correlation of STDs, which is sexually transmitted disease, and as a predictor of the risk of AIDS.

Mr. Speaker, this chart shows that persons living with HIV and AIDS, and this was as of the end of last year, the percentage by gender, 68.4 percent are male; 31.6 percent are females. And then when you begin to look at the ethnicity of it, 72.4 percent are African American or blacks; 23.9 percent are white non-Hispanic; 1.9 percent are Hispanic, and the Hispanic population is growing in our State, so that increase is in some way related to the growth. You see the proportion, that indeed it is growing.

Of the 20,525 individuals reported through December 2000, 10,329 have been reported with AIDS, including 8,189 adult adolescent males, 2,013 adult adolescent females, and 127 children.

According to figures from last year, North Carolina ranked 23rd among 50 States, including the District of Columbia, in terms of the number of AIDS cases. Most North Carolina HIV disease reports highlight the male population, African Americans 72 percent, falling within the age group between 30 and 39. Thirty and thirty-nine are our most active, productive citizens. This is the time when people are forming families and building careers. This is the time when people ought to be the most productive in their community; but at this time we are finding within

the age group 30 to 39, 72 percent are African Americans.

□ 2030

In the First Congressional District as well as in eastern North Carolina, including the third district, African Americans accounted for as much as 87 percent of HIV/AIDS cases that were reported in this year alone, the new cases that were reported.

The House of Representatives and the General Assembly of North Carolina recently passed under the leadership of Representative Wright a resolution declaring HIV/AIDS as a public health crisis, that we need to acknowledge that and get our community involved, get our faith-based community involved and our education system involved, because without the public recognition, we are not going to deal with that.

While only 1 percent of AIDS cases are found among teenagers aged 13 through 19, an additional 18 percent are found among those who are in their early 20s, who may have acquired the infection while they were teens because many of them had the infection, but we are now just discovering it while they are in their early 20s. Likewise, we are finding infection of teenagers is increasing. Additionally, some 26 percent are found among those who are now in their 20s, assuming they might have been infected some years earlier.

As of December 31, 68 percent or 13,943 of all HIV disease reports in North Carolina were among those who were from 20 to 39, regardless of race. From 20 to 39. That is an astounding, large number of people. Let me repeat that: 13,943 were reported last year. Of those reported, 68 percent of those reported were between the ages of 20 and 39.

Now, earlier I had said that there was a correlation between STD, sexually transmitted disease, as a predictor of HIV.

I want to show you another chart as well. This is alarming because syphilis and gonorrhea and other transmitted disease, we thought those had been eliminated. In fact, I have a map that I do not have with me; but if you look at this map, it is almost completely eliminated, other than in the South and in one or two places in the Midwest. Completely eliminated. In fact, there is no reason why sexually transmitted disease should be growing. There indeed is a bacterium treatment for it, but it is growing in the South; and it is growing in my State in alarming numbers.

Although it cannot be said that the STDs cause HIV/AIDS, it can be said there is a correlation between them. Indeed, you can begin to see the large number of them growing in North Carolina. But also you see a high percentage of them being related to African Americans. Gonorrhea percentage, almost a relationship between what you see in gonorrhea and syphilis as the HIV chart. There is no reason for

this. This is unexplainable why this is happening. One is a disease by a behavior pattern that we can correct, but also there is no public outcry in understanding this. One, we assign to the fact, well, this is their own doing and, therefore, we shouldn't be concerned.

There is a glaring racial disparity in North Carolina cases. Seventy-one percent of them are among African Americans. The infectious syphilis rate is almost 12 times greater for African Americans, 11 times greater for Native Americans, and eight times greater for Hispanics than the rate for non-Hispanic whites.

In 1998, half of all syphilis cases were confined to 1 percent, 1 percent now, of all the counties in the United States. These cases of syphilis were found in 28 counties, primarily located in the South, and three independent cities: Baltimore, St. Louis, and the District of Columbia. North Carolina had five nationally significant high syphilis morbidity counties: Guilford, not in my district, but certainly a large county in my State; Forsyth, again not in my district, but a large county in my State; Mecklenburg, which is our largest city; Wake County, which is our capital; and Robeson County, growing at significant rates higher than all of the other southern States.

The National Alliance of State and Territorial AIDS Directors, something called NASTAD, did a report. I have that report. This report is entitled "HIV Services in Rural Areas." They studied New Mexico and South Carolina experiences.

Mr. Speaker, I include this study for the RECORD.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS, NASTAD MONOGRAPH, EXECUTIVE SUMMARY

HIV SERVICES IN RURAL AREAS

Introduction

AIDS cases in rural areas (less than 50,000 persons) represented approximately five percent of all reported AIDS cases in 1995. Patterns of HIV infection suggest that the epidemic is spreading in rural regions of the United States. Estimating the prevalence of HIV infection, based on AIDS cases, is complicated by the tendency of rural residents to go to urban areas for diagnosis and treatment, if possible. Research findings indicated that the majority of HIV infections in rural areas tend to occur in young adults (15-29 years), primarily females. Rates of heterosexual transmission are more prevalent than homosexual transmission and appear to be compounded by the presence of other sexually transmitted diseases and the use of crack/cocaine. Geographic areas with populations of 50,000 or fewer residents are considered rural. In 1997, over 54 million Americans lived in rural areas, composing 20 percent of the U.S. population (see Appendix A).

The HIV/AIDS Bureau (HAB) has set, as part of its policy agenda, an objective to document the experience of vulnerable populations and the changing nature of the epidemic. One population that has been historically under served is rural residents. In response, the National Alliance of State and Territorial AIDS Directors (NASTAD) developed this monograph on HIV Services in Rural Areas, as part of a cooperative agreement with the HIV/AIDS Bureau (HAB),

Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services.

HIV Services in Rural Areas describes approaches that states are using to address the health care and social service needs of rural residents living with HIV/AIDS. NASTAD selected two states, New Mexico and South Carolina, to highlight in this monograph because they are located in regions of the United States that are considered rural. Additionally, these two states were selected because their populations include a disproportionately high number of rural communities of color—African, Hispanic, and Native Americans—who are very high risk populations for new HIV infections—living in areas with limited resources to address their health care needs (see Appendix B).

NASTAD conducted interviews with the state AIDS directors and program staff and local providers in both New Mexico and South Carolina in fall 1999. Based upon these interviews, NASTAD identified barriers to access to HIV health care and key program components that support and link HIV health services in rural areas.

Barriers to Providing HIV Services in Rural Areas

Long Distance Travel—Almost every service provider interviewed for this monograph identified transportation as a barrier to overcome in the provision of services for persons living with HIV/AIDS in rural areas. Providers acknowledged that travel options exist: 1) commercial transportation services; 2) volunteer drivers; 3) staff home visits, or 4) mileage reimbursement for the use of a personal vehicle. However, in cases of acute illness, the lack of an adequate transportation plan may make a critical difference.

Inadequate Supply of Health Care Providers with HIV/AIDS Expertise—Providers express frustration about the lack of physicians with expertise in HIV treatment, despite the wide availability of training and consultation opportunities. They also reported that it is difficult to monitor the quality of care that persons living with HIV/AIDS receive from local health care providers and that these providers, in turn, may not be highly motivated to monitor care due to small client caseloads. In the absence of local medical expertise, a social service provider, such as a case manager, may become the local "HIV expert." In cases in which the provider has little or not medical training, serving as the local expert is a difficult and isolated job because clients living with HIV and their families rely on this individual for a breadth of information that she or he may or may not be able to provide.

Linking HIV Counseling and Testing with Care—Many of the providers reported having either formal or informal relationships with local counseling and testing sites. Despite these linkages, providers also reported that a large number of person living with HIV/AIDS, as high as 50% for some, are referred to services either from hospitals or emergency rooms. While many of these clients are receiving their diagnosis for the first time, others are aware of their HIV status but have not sought services. Some providers report relying heavily on "word-of-mouth" to reach clients but acknowledged that stronger ties between testing sites and other organizations that may be in a position to refer clients need to be developed.

The Lack of Available Medical Facilities—Since the early 1980's, the number of rural hospitals and medical facilities has dwindled primarily due to financial cutbacks. Many facilities have closed or have been consolidated with other organizations or agencies, or the number of services has been drastically reduced due to managed care penetration, or the disappearance of an adequate

supply of specialist, or the need to acquire new and expensive technology. Such trends have exacerbated the limited supply of comprehensive health care services needed by rural residents living with HIV/AIDS.

Limited Availability of Social Services—Rural areas, especially poor ones, may have few agencies to provide social or support services. The lack of available services restricts opportunities for agency and/or organization collaboration and prevents the formation of service networks. Linkages to community-based social service agencies have become more critical as HIV has become a chronic condition and clients' needs have become more diverse.

The Stigma Attached to HIV/AIDS—The stigma attached to HIV/AIDS may result in community-wide denial that HIV is a problem that needs to be addressed. Medical providers may resist treating persons living with HIV/AIDS. In contrast, clients may be reluctant to seek services in rural areas "where being socially ostracized.

In addition, there may be a sense of mistrust of medical and related health care providers by individual clients and/or the community at large, especially if such service providers are unknown to the client or from outside the local community.

Client Adherence to Treatment—With improved HIV/AIDS care and treatment, treatment adherence may become a more important concern. Promoting adherence to antiretroviral treatment regimens can be difficult when clients are isolated and face-to-face contact between case managers, physicians, treatment educators and persons living with HIV/AIDS is limited. It also is difficult to assure client adherence to treatment on a regular schedule if the ability to refill prescriptions is problematic, or if the client has issues of stigma to overcome.

Substance Abuse—Several providers noted that the provision of long-term substance abuse services is a significant service delivery barrier in rural areas. Distance and limited client contact compound the challenge. Substance abuse treatment services may not be readily available outside of urban areas. There may be a sense of denial, both in the community and on the part of the clients who are using drugs and alcohol, because substance abuse is not identified openly as a problem in rural areas, resulting in little effort to secure treatment services.

Addressing the Special Needs of Communities of Color in Rural Areas—Communities of color, including Africans, Hispanic, Native, and Asian Americans, are at high risk for HIV infection. Rural communities of color, like other rural residents, experience the same barriers—stigma, poverty, and the absence of accessible care vulnerability of these communities to HIV is further compromised by additional factors: discrimination, distrust of the medical establishment and the health care system, diverse nationalities, language differences, severe poverty and unemployment, and social-cultural differences and isolation.

State Components that Link HIV Services in Rural Areas

The providers interviewed for this monograph have developed and described various strategies for providing HIV services to clients living in rural areas based on client needs and available resources. State strategies include:

Addressing Clients' Needs Beyond HIV—Service providers who address the entire range of client needs are more likely to maintain clients in care. Poverty, substance abuse, mental illness and other problems that are often associated with urban life also affect people living in rural areas. For example, the Palmetto AIDS Life Support Serv-

ices (PALSS), in Columbia, SC, operates the Women's Resource Center. Approximately 25 percent of PALSS clients live in rural areas. The center provides a range of services that address the needs, both HIV-related and those not related to HIV, of their female clients. PALSS offers parenting classes, breast and cervical cancer screening, nutrition classes, exercise classes, social activities such as crafts and sewing classes, and a library with resources specific to women and HIV, creating a link between service provider and client.

Client-Centered Approach—It is not always practical to develop services targeting a specific population in a rural area. The caseload is often small and resources are extremely limited. These circumstances necessitate that staff be culturally sensitive and focus on the clients as individuals, since the client population, though small, may be very diverse. For example, one of New Mexico AIDS Services' (NMAS) case managers is Native American and works with the organization's Native American clients in Albuquerque. The case manager also understands the cultural importance of using Native American healing methods and administers NMAS's complementary medicine program.

Flexibility—Service providers stressed the importance of designing and administering programs that are flexible enough to accommodate the unique needs of individuals living with HIV/AIDS. Many agencies allow clients to designate where they will meet with their case managers, whether at their home, a local health department or library, or even for lunch at a local restaurant. Such arrangements require additional driving on the part of case managers and allows the client to identify a "safe site" in his or her community where individual confidentiality can be maintained. Limited clinic hours present another challenge for providers. If a person living with HIV/AIDS cannot schedule an appointment during regular clinic hours and needs to see a physician in between weekly clinics, several service providers reported that the physicians will frequently allow office visits, even though they are contracted to do so.

Working with Available Resources—It is important to identify and to link collaborative partners in rural networks, even with limited resources. For example, the Edisto Health Department in central South Carolina works with the Cooperative Church Ministries of Orangeburg (CCMO), a coalition of churches in the area that have combined their resources to offer some services such as a small food and clothing bank to persons living with HIV/AIDS. CCMO also administers the Housing Opportunities for People With AIDS (HOPWA) funds for the health department.

Fostering Informal Relationships—Service providers in rural areas stressed the importance of informal relationships that repeatedly prove to be invaluable in identifying resources and developing service networks. These relationships may develop unexpectedly. The ACCESS Network in Hilton Head, SC works closely with "Volunteers in Medicine," a medical clinic staffed by retired health care professionals, who moved next door to ACCESS several years ago. Some ACCESS clients now receive services at the clinic. Case managers work closely with the clinic's staff to coordinate clients' care. They also provide clinic staff with information on HIV/AIDS treatment developments.

Providers reported fostering informal relationships between their own physicians and infectious disease (ID) specialists outside their service area who are available for phone consultation. Providers also cited the importance of working with local media to raise awareness about HIV/AIDS and the

agency's services by running public service announcements (PSAs) or providing coverage of agency activities and events.

Conclusion

Both New Mexico and South Carolina have implemented strategies that seem to be working well for their respective residents who are living with HIV/AIDS. Both states also have found it necessary to remain flexible in implementing these strategies to meet the needs of specific group of residents who have unique challenges from one geographic area to another within each state. The selection of these two states in no way suggests that other states are not conducting exemplary work to assure positive outcomes for their respective residents. The selection of these states simply presents an opportunity to share information about HIV services in rural areas with other jurisdictions and stimulate national discussion among states on how best to meet the needs of persons living with HIV/AIDS.

HIV SERVICES IN RURAL AREAS: THE NEW MEXICO AND SOUTH CAROLINA EXPERIENCES

INTRODUCTION

AIDS cases in rural areas represent approximately five percent of the all AIDS cases in the United States. Long distances between residents and accessible health care services, social isolation as a result of social stigma related to HIV/AIDS, lack of adequate, if any, health insurance coverage, insufficient medical facilities, few medical specialists, and limited support services like transportation and child care challenge the efforts of rural communities (see Appendix A) to serve residents living with HIV/AIDS.

State health departments, in collaboration with local health agencies and organizations, are focusing on preventing new infections in rural areas, getting persons living with HIV into care (see Appendix B), and improving access to HIV health care services in rural areas. State health departments offer experienced insight, methodological research and analysis, and documented evidence of the success or failure of specific program strategies that collectively are designed to improve the quality of life for persons living with HIV/AIDS. State health departments also have the expertise to provide technical assistance and support for capacity building to local health care agencies and organizations that serve persons living with HIV/AIDS and to develop linkages between HIV/AIDS health care and related services in urban as well as rural areas.

HIV Services in Rural Areas is a monograph developed by the National Alliance of State and Territorial AIDS Directors (NASTAD), under a cooperative agreement with the HIV/AIDS Bureau (HAB), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services. NASTAD conducted interviews with state AIDS directors and local service providers receiving Ryan White CARE Act funds in fall 1999. This monograph highlights activities in New Mexico and South Carolina, two states that have developed strategies to address the primary care and support service needs of people living with HIV/AIDS in rural areas. These two states were selected because they are located in regions of the United States that are sparsely populated and are characterized as rural with remote populations. Additionally, these two states were selected because their populations include a disproportionately high number of rural communities of color—African, Hispanic, and Native Americans—who are at high risk for new HIV infections.

NEW MEXICO

Total Population: 1,737,000.
Area: 121,593 sq. miles.

Population Density: 14 persons per sq. mile.

HIV/AIDS Cases (cumulative reported through June 1999) (HIV reporting was initiated in January 1998).

People living with HIV/AIDS (reported): 1,334.

AIDS cases reported in 1999: 125 (annual rate per 100,000 population: 7.2).

HIV cases reported in July 1998-June 1999: 318.

Cases of AIDS reported (Cumulative through June 1999): 1,866.

Ryan White CARE Act Title II Base Grant Award, FY 1999: \$1,125,079.

ADAP, FY 1999: \$1,351,076.

Total Title II Funds, FY 1999: \$2,476,155.

Over 75 percent of the cases of HIV/AIDS reported in New Mexico are attributed to male to male sexual contact (MSM). Women compose only eight percent of reported cases of HIV/AIDS. Fifty-six percent of persons reported with HIV/AIDS are white, 35 percent are Hispanic, five percent are Native American, and four percent are African American. Over two-thirds of HIV/AIDS cases are reported in Bernalillo and Santa Fe Counties, where the cities of Albuquerque and Santa Fe are located. The number of cases reported in New Mexico's other 31 counties range from zero to 124.

In July 1997 the HIV/AIDS/STD Bureau of the New Mexico Department of Health (DOH) created the HIV/AIDS Medical Alliance of New Mexico (HMA). The HMA is a capitated system that provides medical care, case management, home care, support services including counseling, housing and nutritional assistance, and work re-entry programs through partnerships among regionally-based organizations.

Under the HMA system, the state is divided into four districts: Albuquerque, Santa Fe, Las Cruces, and Roswell. Each of the four HMAs is a self-contained, multidisciplinary provider or an association of providers, designed to provide cost-effective continuum of care including a prevention focus. Racial/ethnic distributions for HIV/AIDS caseloads in each of the four HMA districts is reported in Appendix D.

The HMA model resulted from a field review commissioned by DOH in November 1996. The review was conducted to identify and clarify shifts in the case and treatment of persons living with HIV/AIDS, such as the introduction of antiretroviral combination therapy and the impact of deeper penetration of managed care health care into both the urban and rural areas of the state. These shifts necessitated an examination of the statewide HIV/AIDS service system and consideration of new models of case management and service delivery.

The field review involved an inventory of existing services within each of the four districts. The review included: (1) an examination of each contract managed by the state HIV/AIDS/STD Bureau; (2) the identification of services provided through other agencies such as the Veterans Administration and the Indian Health Agency; and (3) a review of the HIV Coordinating Council's services guide. Epidemiological data was used to assess the density of client access to the available services.

In addition to the review, task forces were organized in each district. These task forces were composed of representatives from community-based organizations, clinical systems, regional DOH agencies, advocacy groups, and home care and prevention agencies. The insights from these groups on access to services, competence of service providers, completeness of service continuums, and gaps in services were invaluable to the process.

The findings of the review process identified needs in rural areas of the state. The final report states:

Access to adequate services diminishes the further away from Santa Fe or Albuquerque one lives. Taos, Los Alamos, Roswell, Las Cruces, and Farmington provide pockets of services that meet the immediate needs of many persons living with HIV/AIDS. The rural regions from the four corners of the state are underserved and force persons living with HIV/AIDS to relocate, to drive long distances, or to cross state lines to pursue adequate services. Many in the task forces reported that while there were physicians available to see persons living with HIV/AIDS, their knowledge about the disease was insufficient and resulted in misdiagnoses of opportunistic infections and inappropriate treatments. Physician HIV/AIDS competency is a serious issue in rural areas (Finney, 1999).

HMAs Respond to Local Needs

FUNDING FISCAL YEAR 1999

District	State funds	CARE Act funds	Total
District 1	\$730,000	\$115,000	\$845,000
University Hosp.*	\$270,000	\$115,000	\$385,000
District 2	\$509,000	\$115,000	\$624,000
District 3	\$170,000	\$115,000	\$285,000
District 4	\$95,500	\$115,000	\$210,500

(* University Hospital has a separate contract to provide primary care in District 1.)

The HMA system allows HIV case management to be specialized within an agency and specific to the needs of persons living with HIV/AIDS. Before the HMAs, the state sub-contracted with approximately 100 providers. Most of the providers did not specialize in HIV services and there was great variation in the case management services provided. The formation of the HMAs resulted in statewide availability of comprehensive case management and support services for persons living with HIV/AIDS.

Consolidation has been an important part of the HMAs. With the establishment of the HMAs, person living with HIV/AIDS enroll in and receive services from only one organization. Referral to services is facilitated because there is only one access point in each district and HMAs have publicized their services throughout their service area. Clients receive all necessary services from one provider, not various providers scattered throughout the region. Accessing services from several providers greatly increased the possibility of breaches in confidentiality, a major concern for persons living with HIV/AIDS in rural areas.

Service providers for each district were selected through a state request for proposal (RFP) process. The state review process identified services considered necessary for an integrated continuum of care for persons living with HIV/AIDS and their families. Findings from the state review process were used to develop the HMA model. Applicants are required to provide the identified services either directly or through contracts with other organizations. Providers have contracts for three years.

Key Factors in the Development of HMAs

According to Donald Torres, Section Head of the New Mexico's DOH, HIV/AIDS Bureau, the HMA model works well for low incidence, rural states where the number of service providers is relatively small. Under these conditions, the service delivery network is compact enough that adjustments can be easily made across the program.

At the time of model was being considered there were only a few HIV-specific providers in the state. DOH contracted with various organizations throughout the state to provide case management services but the contracts were not large enough to jeopardize the agencies' viability if funding was discontinued.

Therefore, most service providers did not resist the formation of the HMAs because it would not negatively impact the well-being of individual organizations.

Clients also were generally in favor of some change to the existing system. The development of the HMAs paralleled the move toward Medicaid managed care in the state which created an environment where people expected change in the health care delivery system. As with any major change, the move toward HMAs created some concerns. The HMAs were caught up in the partisan political debate on managed care. Additionally, there were concerns that the HMAs would not be sensitive to the needs of people of color and that they might divert funds from HIV prevention programs.

*Two Years Later * * **

Since their establishment, HMAs have become identified as the source of HIV care in New Mexico. Of the approximately 1,300 persons living with HIV/AIDS, 1,100 persons living with HIV/AIDS access case management services throughout the HMAs.

In New Mexico, anyone who tests positive for HIV is eligible for case management services. To be eligible for services through the HMA a person must: 1) have a documented diagnosis of HIV disease from a qualified licensed medical provider; 2) be a resident of the service area (district); and 3) have a documented income at or below 300% of the federal poverty level (FPL). Members may elect to enroll in a HMA other than the one providing service where they reside but HMAs do not recruit members from outside their service area.

Since their initiation, the HMAs have been integrated with other HIV services in the state. The DOH operates a health insurance continuation program. The program pays up to \$400 per month for the premiums of a participating client's existing health insurance. The program also reimburses the patient's share (co-pays) for HIV medications under the New Mexico Medication Assistance Program (ADAP). The state will purchase health insurance for eligible clients through NMCHIP, the state's health insurance risk pool. This reduces the amount of money spent by the HMAs for health care services.

The University of New Mexico's Health Science Center (University Hospital), a Ryan White CARE Act (RWCA) Title III grantee, administers the "Partners in Care Program." Medical services are provided at the hospital in Albuquerque and the grantee also recruits physicians across the state to provide services to persons living with HIV/AIDS. To be eligible for the program, physicians must treat a certain number of persons living with HIV/AIDS. University Hospital physicians are available for consultation and the hospital also operates a hotline that physicians may call with treatment-related questions. HMA clients, especially in three of the four districts, often access medical services through the Title III program.

Successful Cost Containment

The New Mexico DOH reports significant cost savings as a result of implementing the HMA model. The cost of providing HIV-related care and support services, including medications, to New Mexico's caseload of persons living with HIV/AIDS climbed from \$5.2 million in 1995 to \$8.2 million in 1996, a 37 percent increase. The increase was primarily due to the expense of antiretroviral combination therapy. Overall costs of care jumped significantly between 1995 and 1996, rose slightly in 1997, then in 1998 fell to the 1996 level. It is estimated that if the HMA system had not been implemented, the cost of HIV care in New Mexico would have increased between five percent and 20 percent

in 1998. HMA implementation saved the state between \$400,000 and \$1.7 million. These cost savings resulted even as the number of people being served increased. The net number of clients served increased by an average of six percent each year.

In the coming year, DOH plans to more thoroughly integrate the Title III grant with the HMA program. Even though training is available for physicians in outlying areas, the HMAs report that care is still problematic and that some physicians lack the required expertise to provide quality HIV care. By integrating the Title III funds into the HMA system, HMAs will be able to select physicians in their districts who are motivated to treat persons living with HIV/AIDS and to develop their HIV-related expertise.

Additionally, these physicians are more likely to work with case managers and persons living with HIV/AIDS in the development of overall care plans.

The state's early intervention nurses also play a key role in linking persons living with HIV/AIDS with services. Five nurses are employed by the state. In post-test counseling, persons living with HIV/AIDS are linked with early intervention nurses who conduct an initial assessment, refer clients to the appropriate HMA, and follow-up clients who do not access care. The nurses also conduct partner notification services.

As of the end of 1999, DOH plans to expand the HMA system. A fifth, statewide HMA will be added that will serve Native American persons living with HIV/AIDS. It will be based in Albuquerque. The state also plans to contract with an agency to provide benefits advocacy services. The new contractor will help persons living with HIV/AIDS obtain benefits and also address emerging needs such as education and re-employment. Additionally, the contractor will provide advocacy services, including mediating grievances with HMAs. The contract will be awarded through a Request for Proposal (RFP) process.

Addressing Needs in Rural Areas

Each of the HMAs has developed a unique service delivery system based on available resources in the district and local challenges. All four districts serve clients who reside in rural areas. Albuquerque (District 1), Las Cruces (District 3) and Santa Fe (District 2) contain urban areas, where most clients reside, surrounded by rural areas. Roswell (District 4) is predominantly rural.

The New Mexico DOH has established different capitation rates for the HMAs based on the greater per client expense of serving clients in rural areas. The larger HMAs, Albuquerque and Santa Fe, are able to achieve some "economies of scale" because they serve a larger number of clients. Additionally, they have access to more resources, including more fundraising opportunities. In rural areas, the distance that clients and staff are required to travel also can escalate costs for mileage reimbursement and staff driving time. To facilitate access for clients in rural areas, all the HMAs reimburse clients for travel expenses (mileage) and all the HMAs have toll-free telephone numbers.

Quality Assurance Activities

DOH has adopted a variety of measures to assure the quality of services delivered by the HMAs. Contracts with the HMAs stipulate the number of clients to be served (a range is specified), the number of contacts with each client per reporting period, travel reimbursement, emergency procedures, and confidentiality and grievance procedures. HMAs are required to maintain records on member enrollment status, provision of covered services, and relevant medical information on individual members. DOH also is administering a client satisfaction survey to

assess whether the HMAs are meeting clients' needs and to determine client satisfaction with the HMA service delivery system.

The New Mexico DOH initiated a process to identify statewide HIV/AIDS "best practices" guidelines to be used to direct the cost-effective design and delivery of HIV/AIDS services throughout the state. The guidelines are intended: (1) to support the management and, where appropriate, the elevation of the quality of HIV/AIDS care throughout the state, (2) to improve access to quality care in both urban and rural areas, (3) to provide a measuring device against which HIV/AIDS care system services might be objectively evaluated, and (4) to provide the HMAs with a product with which they might competitively position their services.

The state guidelines present an integrated "care team" process based on collaboration between primary care physicians, case managers, and the client in the development of an individualized care strategy to delay or reverse disease progression. The guidelines identify core services (clinical, prevention, practical support, educational support and mental health) and procedures for enrollment, assessment, chronic management, acute events and palliative care. To develop the guidelines, DOH held a retreat attended by the executive directors of two HMAs (one urban and one rural), two physicians, three case managers, three persons living with HIV, four early intervention nurses, and representatives of the DOH. Guidelines also have been developed to address case management in rural areas.

Challenges

Accessing Services Based at the Main Office—The HMA has developed alternative approaches for clients living in rural areas because it is not possible to provide all the services that are available at the main office and in the field office in Farmington. For example, clients in rural areas requested that the food bank services be made more accessible. Many were driving long distances (and getting reimbursed for the mileage) for a relatively small amount of food. Now, the HMA purchases gift certificates from the major supermarkets in the rural areas of the district and sends them to clients twice a month. Any client living more than 50 miles from the main office is eligible for the food voucher program.

Obtaining Client Feedback—Providing opportunities for clients to give feedback on their needs and the services they receive can be difficult in rural areas. To facilitate the process, the District 4 HMA holds their Community Advisory Committee meetings at six different sites throughout the service area. The meetings are open to all clients. Local physicians who treat clients also are invited. At the meetings, clients can raise concerns about services or other personal issues. To encourage attendance, dinner is served and incentives, such as grocery store vouchers, are provided. Twice a year, the HMA surveys clients about their needs. Based on the findings of the survey, the HMA will tailor information provided at the meetings to client needs and depending on the topics, the agency's nurse, therapist or other appropriate staff will attend. Treatment issues are always a popular topic at the meetings.

Lack of Medical Providers with HIV Expertise—According to many of the HIV service providers interviewed, local doctors do not take advantage of the availability of training opportunities to increase their knowledge of HIV treatment. In District 4, two physicians treat the majority of the clients. Approximately 12 other physicians see one or two clients. With a large number of physicians providing services and the informal na-

ture of the relationship between the HMA and these physicians, it is difficult to monitor the quality of care clients receive.

The move to consolidate the Title III services with the HMA system will allow the HMAs to focus on a limited number of physicians in the region and build their expertise. Additionally, HMAs that do not have on-site medical services will be able to move toward a care team model with physicians, case managers and persons living with HIV/AIDS working together to develop a treatment strategy. Consolidation will improve the monitoring of clients' medical care.

For more information about the activities of each of the four districts in the New Mexico HMA system, please refer to Appendix D.

SOUTH CAROLINA

Total Population: 3,836,000.

Area: 31,113 sq. miles.

Population Density: 123 persons per sq. mile.

HIV/AIDS Cases (cumulative reported through June 1999) (HIV reporting was initiated in February 1986).

People living with HIV/AIDS (reported): 10,108.

AIDS cases reported in 1999: 984 (annual rate per 100,000 population: 25.7).

HIV cases reported in 1999: 877.

Cases of AIDS reported (Cumulative): 8,352.

Ryan White CARE Act Title II Base Grant, FY 1999: \$4,968,208.

ADAP, FY 1999: \$5,966,180.

Total Title II Funds, FY 1999: \$10,934,388.

The HIV Epidemic in South Carolina—In rural areas of the southeastern United States, the HIV epidemic is increasingly concentrated in the heterosexual population and associated with high rates of sexually transmitted diseases (STDs), especially syphilis, alcohol abuse and crack cocaine use. In South Carolina, 71 percent of HIV/AIDS cases reported in 1998 were among men, 29 percent among women. African Americans made up 75 percent of reported HIV/AIDS cases. Twenty-seven percent of HIV/AIDS cases are attributed to male sexual contact (MSM), including MSM and injection drug use, 27 percent are attributed to heterosexual contact and nine percent to injection drug use (36 percent have no reported risk). One third (33 percent) of the people reported with HIV/AIDS in 1998 reside in rural areas.

Characteristics of Newly-Diagnosed People with HIV/AIDS: Urban vs. Rural—From January 1991–December 1998, the Department of Health and Environmental Control (DHEC) conducted the Supplement to HIV/AIDS Surveillance (SHAS) Project (supported by CDC). The project initially included Charleston County and the Edisto Health District (a three county area). A third county, Richland, was added in 1993. The project staff conducted interviews with newly reported/diagnosed people with HIV/AIDS, 18 years of age or older, who were residents in the study area. During the course of the project, 1,146 eligible persons were interviewed. Of these, 78 percent were from urban communities and 22 percent were from rural communities.

The Rural SHAS Project was implemented in Edisto Health District between January 1995 and December 1996. Seventy interviews were completed as part of this study. The majority of respondents were male (72 percent) and African American (77 percent). Approximately 47 percent of the Rural SHAS participants had never lived outside of the county. The findings of the study include:

At the time of diagnosis, 28 percent of rural participants had AIDS, as compared to 34 percent in the urban counties;

Sixty-one percent of rural participants had 12 years of education or less, as compared to 69 percent in the urban counties;

Sixty-nine percent of rural participants were unemployed at the time of diagnosis, as

compared to 57 percent in the urban counties; and

Sixty-nine percent of rural participants had household incomes of \$10,000 a year or less, as compared to 39 percent in the urban counties.

The study also revealed that participants in rural areas were more likely to have used crack cocaine than those in urban areas (33 percent rural, 28 percent urban) but were less likely to have injected drugs (14 percent rural, 16 percent urban). Rural participants were more likely to have not used condoms with their steady sexual partner (48 percent rural, 38 percent urban) and were less likely to have received money or drugs for sex (12 percent rural, 18 percent urban).

The State Consortia—South Carolina relies primarily on eleven Title II-funded regional consortia to provide primary care and support services to persons living with HIV/AIDS. CARE Act-funded services also are provided by two Title III grantees and one Title IV grantee. The DHEC administers the Title IV grant on a statewide basis that provides mostly tertiary and specialty care and assures that primary care is easily accessible for infants, children, youth, and women infected and affected by HIV. The two Title III grantees that focus on outpatient early intervention and primary care services are based in Columbia, the state's capital, and in Ridgeland, in the southern section of the state. The Ridgeland Title III provider was first funded in fiscal year 1998, so it is still a relatively new component to the service network in this area (note: two new Title III grantees were funded in 1999—Greenville Community Health Center in Greenville and Low Country Health Care Systems in Fairfax). The addition of these two primary care providers brings additional federal resources to two rural consortia).

The state opted for the consortia system due to a lack of support service and medical providers, especially in rural areas. The statewide plan developed in 1990 identified primary medical care as the greatest need in the state. The formation of consortia was seen as a way to stimulate the development of local service networks.

Initially, the state funded consortia in four areas. By 1994, statewide coverage was achieved through the formation of seven more consortia. The consortia basically mirror the geographic boundaries of the state's public health districts to each consortia region also includes a local health department.

The consortia, which vary in size from three to six counties, are charged with assessing needs and resources in their region and developing and maintaining a service delivery network. Each consortium has developed a unique system of care based on existing needs and available resources in the service area. The following variables influenced the development service networks in the consortia:

Existence of AIDS service organizations (ASOs) prior to the formation of the consortium.

Ability of the lead organization to identify and recruit other providers into the services network.

Availability of primary care providers in the service area and their willingness to work with persons living with HIV/AIDS.

Availability of training opportunities and information sources on HIV treatment for primary care providers, and

Access to specialty providers.

Several providers stressed the role personality plays in developing service networks in rural areas. Many relationships between service providers are informal and are forged between staff members in various agencies. Service delivery systems must be flexible enough to allow staff to take advantage of

these informal linkages that can provide access to necessary expertise or resources.

Currently, 39 percent of the state's Title II funds (including ADAP) go to the consortia. Funds received by each consortium are based on the estimated number of persons living with HIV/AIDS in the region, with some variance in the formula due to demonstrated need. Consortia are funded through a request for proposal (RFP) process and awarded funds on a five-year cycle. While the process is designed to be competitive, only a single applicant has applied for each region. Service and reporting requirements are outlined in the RFP and any necessary changes can be made in the annual contracts. DHEC meets quarterly with consortia contacts.

The consortia developed into one of three basic structures:

Lead agency and subcontractors,

Single lead agency providing both primary care and support services, and

Single lead agency providing case management with informal linkages to primary care.

The structure that evolved depended greatly on the resources available in the communities. For example, the Midlands AIDS Consortium, based in Columbia, SC serves both urban and rural areas. The consortium focused on establishing linkages through a system of subcontracts because there already were agencies providing HIV-related services. In other consortia regions, a single agency was identified and funded to provide HIV-related services that may or may not already have been available in the region.

Quality Assurance—The Ryan White CARE Act Peer Review Committee oversees the activities of Title II consortia in the state. It is made up of eleven members, one for each consortium, and DHEC representatives. When the committee was formed in 1996, each consortium completed a self assessment. The committee established a mission statement based on the findings of this process. For the last two years the committee was developing standards and guidelines that consortia can use as tools to assess services.

The committee has developed guidelines for case management services and is also developing outcome measures for primary care. To develop the guidelines for case management services, the committee surveyed all case managers in the state and held a series of meetings for additional input. Based on the findings of this process, the committee has developed standards for intake, assessment, and discharge.

State Efforts to Link HIV Services in Rural Areas—While the state relies primarily on the consortia to meet needs in their own regions, the state does conduct activities that assist in the provision of services in rural areas. The state has consolidated the ADAP program in a centralized pharmacy operated by DHEC which allows the state to administer the program in a cost-effective manner while rapidly dispensing medications. Medications are mailed to clients at their homes. Initially, medications were distributed through local health department pharmacies but increases in the number of persons living with HIV/AIDS soon exceeded the capacity of the regional pharmacies to carry out the necessary services.

A major advantage of the centralized pharmacy approach is that it allows DHEC to assess adherence to U.S. Public Health Service treatment guidelines through monitoring prescriptions for persons living with HIV/AIDS in rural areas. DHEC pharmacists review prescriptions for any deviation from the standard protocol. If an irregularity is identified, the physician is contacted to find out why the medications were prescribed and to discuss treatment decisions before the pre-

scription is filled. This provides a training opportunity for physicians in rural areas who may not have treated a large number of persons living with HIV/AIDS and may lack expertise in HIV treatment.

Local providers frequently report the shortage of physicians with expertise in HIV treatment. The state employs a Title II-funded medical consultant who is available to consult with physicians. All physicians treating HIV are encouraged to develop an informal relationship with the medical consultant. For the Title III providers, the state plans to move toward a primary provider model, in which persons living with HIV/AIDS access medical services through a physician in their community who has access to specialty providers who can be contacted for either consultation or referral.

Challenges

Serving a Large Region—Initially, most of the services provided by the CARETEAM, the lead agency of the Waccamaw Care Consortium and based in Myrtle Beach, were concentrated in Horry County, near Myrtle Beach, and all staff members resided in this area. To meet with clients in the two southern counties required staff to make a round trip from the agency's office in the northern part of the service area. To alleviate some of this travel, case managers who reside in the outlying counties were hired. On days when case managers see clients in the southern part of the service area, these case managers do not go into the office to reduce driving time. Staff also may see clients at either the beginning or the end of the day, before or after they have been to the office.

Within a large service area, outlying areas may have access to fewer services and feel less connected to a service provider. In addition to improving services for clients, hiring staff from that area help to facilitate linkages with the community. CARETEAM found that as they increased their presence in the two southern counties, it was much easier to work within these communities in terms of raising awareness of HIV and of CARETEAM services.

According to Jeff Kimbro, Executive Director of CARETEAM, "We have worked hard to make sure that Georgetown and Williamsburg Counties feel they have a stake in the organization and know that we are here to serve them. Even though these counties will never have the same level of resources as Horry County, as we've expanded our efforts in the area we have seen the community gradually become more involved in the response to the epidemic."

Knowledge Level of Primary Care Providers—Because it does not have physicians on staff or have contracts with medical providers, the ACCESS Network has had to work hard to assure that physicians in the service areas have access to information on the treatment of HIV. Located in Hilton Head and Hampton, ACCESS Network is the lead agency for the Low Country Care Consortium. According to Jerry Binns, President of ACCESS Network, physicians have become much more knowledgeable about HIV in the past few years but it is still necessary to provide educational opportunities.

ACCESS Network has used a variety of approaches. They regularly provide written materials on treatment developments to local practitioners. They also hold informal meetings between ACCESS Network staff and local practitioners, organize educational presentations by experts (sometimes done with support from pharmaceutical companies), and foster relationships between local practitioners and HIV experts in the state who are available for phone consultation. While knowledge level is important in terms of the quality of care, ACCESS Network acknowledged that the stigma attached to HIV

is still a barrier in terms of physicians' willingness to treat persons living with HIV/AIDS. Other deterrents include a fear of being perceived as an "AIDS doctor," the perception that HIV/AIDS needs to be treated by a specialist, the potential financial costs of treating people with HIV (low reimbursement rates), scheduling time to attend training activities and the distance providers must travel for training. For more information about each of South Carolina's consortium, please refer to Appendix E.

CONCLUSION

State Efforts that Support HIV Services in Rural Areas

Local providers in both states identified several ways that the state HIV/AIDS Program (Title II grantees) can support the delivery of HIV services in rural areas in program components that are often difficult to resolve.

Assistance in Diversifying Funding Sources—Although sources of financial support can be limited in rural areas, service providers expressed concern about being overly dependent on the state and the Ryan White CARE Act for funding. Rarely do rural areas have access to a fundraising base or grant opportunities from foundations and corporate donors as do service providers in urban areas. Providers also acknowledged that many do not possess the organizational capacity to conduct fundraising activities or prepare grant proposals and/or contracts. Providers suggested that states provide technical assistance on fundraising, grant writing, and financial and organizational capacity building. States may have the resources to hire a fundraiser who can focus on identifying new sources of funding for HIV services for rural areas. States can assist in identifying funding sources in the private sector and pass information about such sources to providers at the local level.

Identification of Outcome Measures—States can play a role in initiating and maintaining a process to develop outcome measures for rural medical and support services. While conducting this type of program evaluation can mean additional work for providers, it helps them to focus on the effectiveness of their services, account for funds, and demonstrate that they are improving the health status of persons living with HIV/AIDS in rural areas in which they provide services.

Fostering Ryan White CARE Act Cross-Title Collaboration—Especially in rural areas, service providers can be separated by significant distances making the establishment of linkages more difficult. The absence of established links, especially in areas in which other CARE Act providers (Title III, IV, and SPNS) are present, but are not participating in the state's Title II-funded activities, can lead to duplication of and/or significant gaps in service delivery. States can play a role in facilitating cross-title collaboration within service areas to assure more coordinated service delivery.

Strengthening Prevention Efforts—Rural areas can be more conservative than urban areas and more resistant to HIV prevention efforts. The lack of prevention efforts can result in less public awareness which, in turn, may reinforce the perception that HIV is not a problem in rural areas. This lack of awareness on the part of the public, especially in rural areas, may lead to increased spread of HIV and delays in accessing services. Since states administer HIV prevention funds as well, they can provide leadership in recommending or mandating HIV prevention programs at the local level and providing technical assistance in implementing such programs. Additionally, states can move to strengthen linkages between HIV counseling

and testing services and HIV-related primary care and support services to facilitate access to care.

State Responses to the Challenges of Serving Persons Living with HIV/AIDS—Both New Mexico and South Carolina have implemented strategies that seem to be working well for their respective residents who are living with HIV/AIDS. Both states also have found it necessary to remain flexible in implementing these strategies to meet the needs of specific groups of residents who have unique challenges from one geographic area to another within each state. The selection of these two states in no way suggests that other states are not conducting exemplary work to assure positive outcomes for their respective residents. The selection of these states simply presents an opportunity to share information with other jurisdictions and stimulate national discussion among states on how best to meet the needs of persons living with HIV/AIDS in rural areas.

INTERVIEWS

NEW MEXICO

David Barrett, HMA Director, District 2, Southwest C.A.R.E. Center, Santa Fe, 505/986-1084.

Kathleen Kelly, HMA Director, District 1, New Mexico AIDS Services, Albuquerque, 505/266-0911.

Kari Maier, HMA Director, District 3, Camino De Vida Center for HIV Services, Las Cruces, 505/532-0202.

Jane Peranteau, HMA Director, District 4, Pecos Valley HIV/AIDS Resource Center, Roswell, 800/957-1995.

Donald Torres, Section Head, HIV/AIDS Program, Infectious Disease Bureau, Public Health Division, New Mexico Department of Health, 505/476-3629.

SOUTH CAROLINA

Department of Health and Environmental Control

Lynda Kettinger, Director, STD/HIV Branch, Division of Preventive and Personal Health, 803/898-0749.

JoAnn Lafontaine, RWCA Coordinator, STD/HIV Branch, Division of Preventive and Personal Health, 803/898-0752.

Low Country Care Consortium

Jerry Binns, President, ACCESS Network, 843/681-2437.

Ann Driessen, Case Manager, Beaufort-Jasper Comprehensive Health Services, Ridgeland, 843/987-7458.

Midlands Care Consortium

Pat Derajtys, Nurse Practitioner, Department of Internal Medicine, University of South Carolina School of Medicine, 803/540-1000.

Carmen Julius, Executive Director, Palmetto AIDS Life Support Services (PALSS), 803/779-7257.

Nancy Raley, Executive Director, Midlands Care Consortium, 803/540-1000.

Michelle Rojas, Title III Project Coordinator, Richland Community Health Care Association, 803/799-8407.

Pee Dee Care Consortium

Karen Beckford, Executive Director, Help for the Pee Dee, 843/667-9414.

Tri-County Interagency AIDS Coalition

Carl Humphries, Communicable Disease Supervisor, Edisto Health Department, 803/533-7229.

Waccamaw Care Consortium

Jeff Kimbro, Executive Director, CARETEAM, 843/236-9000.

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APPENDIX A: FEDERAL DEFINITION OF A RURAL AREA

One of the challenges of addressing needs in rural areas from a policymaker's perspective is that the term "rural" is not easily defined. Of the various definitions, two of the most commonly used by federal programs were developed by the Office of Management and Budget (OMB) and the Bureau of the Census. Both of these definitions establish a quantitative measure to define rural.

The Bureau of the Census defines an urbanized area (UA) by population density. Each UA includes a central city and the surrounding densely settled territory that together have a population of 50,000 or more and a population density exceeding 1,000 people per square mile. A UA may cover parts of several counties. Additionally, places (cities, towns, villages, etc) with a population of 2,500 or more outside of a UA are considered to be an urban.

OMB designates Metropolitan Statistical Areas (MSAs) as one city with 50,000 or more inhabitants or an urbanized area (defined by the Bureau of Census) with at least 50,000 inhabitants and a total MSA population of at least 100,000 (75,000 in New England). Each MSA must include the county in which the central city is located and additional contiguous counties that are economically and socially integrated with the central county. Any county that is not included in an MSA is considered to be non-metropolitan. Periodically, OMB reclassifies counties on the basis of Census data and population estimates.

It is generally agreed that in rural areas, unless additional encouragement or support is provided, easy geographical access to health and social services is lacking. However, the definitions start to get blurry when considering some metropolitan counties that are so large they contain small towns and rural areas. By one estimate, based on 1980 decennial census data, of the slightly over 32 million persons who live in large metropolitan counties, approximately two million lived in small towns and rural areas without easy geographical access to central areas (Goldsmith, 1993).

APPENDIX B: CHARACTERISTICS OF U.S. RURAL POPULATION

In 1997, over 54 million Americans lived in rural areas, making up 20 percent of the U.S. population. During much of the 1990s, the rural population grew faster than urban populations.

Race/Ethnicity—Eighty-three (83) percent of rural residents are white, as compared to 69 percent of urban residents. African Americans make up nine percent of the rural population and 14 percent of the urban population. Hispanics account for five percent of the rural population and 11 percent of the urban population.

Income Level—In 1996, real per capita income in rural areas was \$18,527 as compared to \$25,944 in urban areas. Sixteen percent of rural residents live in poverty as compared to 13 percent of urban residents. Poverty is especially high among rural minorities with 35 percent of African Americans, 33 percent of Hispanics, and 34 percent of Native Americans in rural areas living in poverty. In comparison, 27 percent of African Americans, 27 percent of Hispanics, and 29 percent of Native Americans living in urban areas live in poverty.

Unemployment—In 1997, unemployment in rural areas was 5.2 percent as compared to 4.9 percent in urban areas.

Health Insurance—In 1996, 46 percent of rural residents lacked private health insurance as compared to 38 percent of urban residents.

Access to Health Care Providers—Over 22 million rural Americans live in areas that are designated Primary Care Health Professional Shortage Areas (HPSAs).

Source: "Facts about the Rural Population of the United States," Rural Information Center Health Service, August 1998.

APPENDIX C: CHARACTERISTICS OF COMMUNITIES OF COLOR AT RISK FOR HIV/AIDS

Although African Americans account for approximately 13 percent of the U.S. population, they represent 36 of all AIDS cases and 45 percent of all new HIV infections. Similarly, Hispanic Americans constitute approximately 8 percent of the U.S. population, but account for 18 percent of all AIDS cases and 22 percent of new HIV infections. Risk for HIV infection may be compounded by diversity in nationalities and cultural practices, language and poverty.

Native Americans often live in geographically remote areas in the United States. Native Americans represent less than one percent of the total United States population and comprise at least 557 federally recognized tribes with each tribe having its own traditions, beliefs, and cultural practices. Approximately 1,800 cases of AIDS have been reported among Native Americans through 1997.

Asian Americans have come to the United States from more than forty countries and territories and speak more than one hundred languages and dialects. Generally, Asian Americans live in more urban areas, as opposed to remote rural locations. As HIV/AIDS infections increase throughout South and Southeast Asia, the likelihood of a rise in new infections among Asian Americans accelerates as families traverse back and forth between their home countries and the United States.

APPENDIX D: NEW MEXICO AIDS SERVICES; DESCRIPTIONS OF FOUR HMA DISTRICTS

District 1, Albuquerque (Counties served: Bernalillo, Cibola, McKinley, Sandoval, San Juan, Socorro, Torrance and Valencia).

Caseload—495 clients.

Client Characteristics:

Male: 90%, Female: 10%.

African American: 4%, Hispanic: 37%, Native American: 7%, White: 50%.

Clients with a third party payer: 36%.

Rural clients: 14% (any client residing outside of Bernalillo County).

Capitation Rate:

Case Management: \$221 per client/month.

Primary Care: \$109 per client/month.

The state contracts with two agencies, both based in Albuquerque, to provide services in the District 1 HMA. Since initiation of the HMA, New Mexico AIDS Services (NMAS) and the University of New Mexico, Health Science Center, Infectious Disease Clinic have worked closely to coordinate case management services and primary care,

even though services are provided at separate sites. In 2000, both case management/support services and clinical care will be available at one location in Albuquerque. The HMA also has a field office in Farmington, New Mexico. One case manager is based in Farmington and clients in outlying areas can either access primary care in Albuquerque or from local physicians funded through the Title III program. If a client does choose to travel to Albuquerque, mileage is reimbursed.

The case manager in Farmington will make home visits or meet clients at a designated location. The Farmington case manager carries a caseload of approximately 40 clients, in comparison to the 48–55 clients served by case managers in Albuquerque because of the additional travel time required.

Regional community task force meetings are held four times a year for clients, families, and rural providers. Two of the meetings are held in Farmington and two are held in other regions of the HMA. The meetings allow an opportunity for clients to provide feedback on services. Dinner is provided at the meeting to encourage attendance.

District 2, Santa Fe—(Counties served: Colfax, Harding, Los Alamos, Mora, Rio Arriba, San Miguel, Santa Fe, Taos, and Union)

Caseload—285 are enrolled in the HMA—the maximum stipulated in the contract with the state (of a total of 317 clients).

Client Characteristics:

Male: 90%, Female: 10%.

African American: 2%, Hispanic: 39%, Native American: 4%, White: 54%.

Clients with a third party payer: 94% (43% are on CHIP).

Rural clients: 43% (any client residing outside of the City of Santa Fe).

Capitation Rate:

Under 300% FPL: \$305/mo.

Over 300% FPL: \$50/mo.

The District 2 HMA is administered by the Southwest C.A.R.E. Center (SCC), an AIDS service organization (ASO) based in Santa Fe. SCC's clinic is staffed with physicians, nurses, and case managers and provides one-stop shopping for clients. Centralized services have allowed SCC to adopt a care team model, in which the case manager, physician and client work closely to determine an appropriate course of treatment and support for the client.

Many clients in outlying counties prefer to go to Santa Fe, if at all possible, because of the quality of primary care services provided at the Santa Fe clinic. Mileage is reimbursed to all primary care and case management appointments. For those who prefer not to or cannot go to Santa Fe, case management services are available in Taos. The two case managers in Taos have about half the caseload of those in Santa Fe due to the travel required to meet with clients.

District 3, Las Cruces—(Counties served: Catron, Dona Ana, Grant, Hidalgo, Luna, Otero, and Sierra)

Caseload—90 clients.

Client Characteristics:

Male: 83%, Female: 16% (1% other).

African American: 3%, Hispanic: 52%, Native American: 2%, White: 43%.

Rural clients: 50% (any client residing outside of the City of Las Cruces).

Capitation Rate:

\$387 per client/month.

Camino de Vida Center for HIV Services is based in Las Cruces, the second largest city in the state. The HMA employs two full-time case managers. A promotor, an additional staff member not funded through the HMA, works with case managers and focuses on trans-border services. The promotor sees clients who travel regularly between the United States and Mexico. Even though more

than half of their caseload is Hispanic, neither of the HMA-funded case managers is bilingual. The agency would like to hire a part-time bilingual case manager. Currently, the client resource coordinator, who is bilingual, will travel to appointments with the case managers when it is necessary.

Case managers see most clients once per month, but the amount of contact depends on clients' need. Case managers make home visits but many clients from rural areas also travel to Las Cruces.

The agency's medical director sees clients at the Las Cruces clinic. Private physicians participating in the state's Title III program provide services outside of Las Cruces. Some clients see a physician in District 4 because it is closer to where they reside and some clients with private insurance go to El Paso for primary care since there is more access to infectious disease physicians there.

District 4, Roswell—(Counties served: Chaves, Curry, De Baca, Eddy, Guadalupe, Lea, Lincoln, Quay, and Roosevelt)

Caseload—82 clients.

Client Characteristics: cell 078

Male: 81%, Female: 19%.

African American: 10%, Hispanic: 36%, White: 54%.

Rural clients: 100%.

Capitation Rate:

\$314 per client/month.

Pecos Valley HIV/AIDS Resource Center is an ASO that provides case management and support services and also conducts HIV prevention activities, including syringe exchange. The agency provides HIV counseling and testing, which serves as a direct link to services for newly diagnosed persons living with HIV/AIDS. However, approximately 50 percent of the HMA's clients first are diagnosed with HIV in the hospital or emergency room.

This HMA does not provide on-site medical services. The staff nurse handles most of the assessment and referral of clients. For example, clients will call the nurse to see if a certain condition is severe enough to warrant a trip to the emergency room or if it can be addressed at their next medical appointment. This approach is more cost effective than having a physician on staff. The HMA has a memorandum of agreement (MOAs) to provide services to their clients with two physicians in the area that are funded through the Title III program.

One case manager is on staff and the agency also contracts with another agency to provide case management services. This agency was providing case management services before the HMA was formed and some of the clients preferred to remain with their original case manager. Case managers get to know clients personally and address their needs on an individual basis because the caseload is small. Contact with the case manager is dependent on client need. Approximately 30–40 percent of clients meet with their case manager at least once every two months. About ten percent of clients come into the office for appointments. The case manager travels to the remaining 90 percent of clients. Travel time can be as long as 3.5 hours one way.

APPENDIX E: SOUTH CAROLINA'S LEAD PRIMARY CARE AND SUPPORT SERVICE AGENCIES

Tri-County Interagency AIDS Coalition—(Counties served: Bamberg, Calhoun, and Orangeburg)

Caseload—355 clients.

Client Characteristics:

Male: 61%, Female: 39%.

African American: 93%, White: 7%.

Uninsured: 70%.

Rural: 100%.

The Edisto Health Department, based in Orangeburg, is the lead agency of the Tri-

County Interagency AIDS Coalition. The health department estimates that there are between 500-700 persons living with HIV/AIDS in the service area and it plans to increase outreach efforts to bring more people into care.

The lead agency administers all the Title II funds received by the consortium. There are few service providers in the area and many support services, such as the local food and clothing banks, are provided on a very limited basis by the local churches. The churches have formed a coalition, called the Cooperative Church Ministries of Orangeburg (CCMO) and combined their resources for a more coordinated approach of helping the community. CCMO administers the Housing Opportunities for People with AIDS (HOPWA) funds for the consortium (writing the checks to the landlords).

The health department employs three nurses (two full-time and one part-time) as case managers. Due to the staffing at the health department, nurses were more readily available than social workers to fill the case manager positions. Case managers focus much of their time on treatment education and arranging access to prescriptions in addition to assuring that the other needs of clients are addressed.

Flexibility is an important element of the relationship between clients and their case manager. Case managers see clients during clinic visits and also maintain phone contact. Since many of the clients are isolated, home visits strengthen the provider/client relationship and the health department believes that face-to-face interaction is important in helping clients adhere to their treatment regimens. The case managers can assess the client's environment and identify factors that may make adherence difficult. For example, a client may live with people who are not aware of his or her HIV status and feels that he or she cannot take medications without having his or her HIV status discovered.

The case managers also will meet with clients at other sites that the client may designate and will drive clients to appointments if they prefer to meet at the agency's office. The disease intervention specialist, who works for the same department that administers the HIV/AIDS program, will visit clients if they are in the area doing partner notification.

The health department provides both primary and specialty care. It contracts on an hourly basis (the most cost effective way for the health department to provide care) with four general practitioners and an Infectious Disease (ID) Physician (there is only a small number of IDs in the state and most are in Charleston and Columbia). The ID physician consults with the four other physicians.

The health department's clinic for clients is open every Thursday from 5-9 p.m. Each week it is staffed by three physicians, including the ID physician. The commitment of the physicians involved is a critical component. For example, some clients are resistant to attending the clinic, whether they fear loss of confidentiality or are just not emotionally prepared in their acceptance of their HIV status. The ID physician will see these clients in his office on a routine or emergency basis. One of the concerns about limited clinic hours is that clients may not have access to care when they need it. For example, if a client calls on Monday with a sore throat, they will have to wait until Thursday to see a physician. If the situation requires, the client is referred to the emergency room.

Once again, transportation can serve as a major barrier for clients attending the weekly clinic. The health department contracts with a transportation service. When they were considering the contract, it was discov-

ered that if they paid by the mile they could only pay a contractor the health department's standard reimbursement rate. This was far too low for a professional provider. Instead, the health department pays the provider a flat fee per week (about \$10,000 per year) to bring clients to the Thursday night clinic. The health department carefully monitors the contract to make sure it is cost effective.

Waccamaw Care Consortium, Myrtle Beach—(Counties served: Georgetown, Horry, and Williamsburg)

Caseload—350 active clients (will serve nearly 450 over the course of the year)

Client Characteristics:

Male: 60%, Female: 40%.

African American: 57%, Hispanic: 1%, White: 40%, Other: 1%.

Uninsured and underinsured: 80%.

Rural: 50%.

CARETEAM, based in Myrtle Beach, is the lead agency of the Waccamaw Care Consortium, which is composed of ten agencies. Horry County is primarily middle class and the other two counties are more rural and have fewer resources. The lead agency provides both medical care and support services. One of the challenges identified in service delivery in the region is that the service area is long and narrow, and the lead agency is located in the northern part of the region. It may take more than 1.5 hours, one way, to travel to the outlying areas because of the geographic configuration of the service area.

CARETEAM employs four case managers. Three have caseloads of about 90-100 clients. The Director of Case Management has a smaller caseload of about 40 clients because this caseload requires more intensive management. Case managers contact clients by phone at least once a month and meet with clients on a face-to-face basis at least once every three months (when applicable). Case managers will meet with clients at the office, clients' homes, or at a designated location.

The agency contracts with five physicians that have been recruited (either paid per month or per patient). Two of the doctors reside in the region. The other three are ID physicians that commute from Charleston. The clinics are operated all day Monday and half day on Tuesday and Wednesday. Limited clinic hours have not been a problem since clients can see a physician during off-hours if necessary. All clinics are held off-site at three physicians' offices located throughout the service area. A key component in the provision of primary care is the medical case manager, who is a medical technician. The medical case manager does all the administrative work, including scheduling appointments, lab work and prescriptions assistance (i.e. state, ADAP, pharmaceutical companies) for the physician to cut down on their work. The medical case manager is present at all the clinics.

Transportation is provided to medical visits by either volunteers or through contracts with individual drivers who are paid by the hour. CARETEAM has used taxis in the past but these proved to be too expensive. While some providers in rural areas have been reluctant to use volunteers to provide transportation, fearing clients will be resistant to riding with volunteers due to confidentiality concerns, this has not been the experience of CARETEAM. In the future, CARETEAM would like to acquire a van and hire a driver on a part-time basis to provide transportation to clients.

Pee Dee Care Consortium—(Counties served: Chesterfield, Darlington, Dillon, Florence, Marion and Marlboro)

Caseload—410 clients.

Client Characteristics:

Male: 65%, Female: 35%.

African American: 96%.

Uninsured: 96%.

Rural: 70%.

Hope for the Pee Dee, an ASO based in Florence, is the consortium's lead agency and the sole recipient of Title II funds. The agency provides case management services and onsite primary medical care. The agency's medical clinic is open three days a week and staffed by a general practitioner. The agency will contract with an ID physician in the near future who will be available for consultation.

The clinic employs three full-time case managers, each with a caseload of approximately one hundred twenty clients. Most of the clients (about 80 percent) come into the medical clinic at least once a month and meet with their case manager at the same time. Case managers contact clients by phone every six weeks. For the majority of clients, medical services are not the top priority. Instead, they are much more concerned with issues related to daily living such as access to benefits, housing, food, and job training.

In the consortium region, access to other community-based support services is limited. Lack of transportation can impact access but there are other challenges. For example, the local food bank recently experienced funding problems that could have jeopardized food services for persons living with HIV/AIDS. As the only agency of its kind in the region, if it had to close, even temporarily, it would have been difficult to arrange an alternative source of food for the agency's clients.

Most clients can find some way to get to the clinic, such as the Rural Transit System, but this travel can be time consuming and inconvenient. The agency will help arrange local transportation and will pay when necessary. The agency would like to either establish a mobile clinic or find physicians in the region who would donate office space in which the agency could hold off-site clinics.

Low Country Care Consortium, Hilton Head—(Counties served: Beaufort, Colleton, Hampton, and Jasper)

Caseload—190 clients.

Client Characteristics:

Male: 58%, Female: 42%.

African American: 65%, Asian/Pacific Islander: 1%, Hispanic: 5%, White: 29%.

Uninsured: 85%.

Rural: 100%.

ACCESS Network, located in Hilton Head and Hampton, is the lead agency for the Low Country Care Consortium, which serves a four-county area in the southeastern section of the state. The service area is about the size of Delaware and Rhode Island combined and has a population of about 200,000. The consortium considers the entire service area to be rural in nature.

ACCESS Network is an ASO providing a full range of support services. In the service area, primary care is provided by various clinics, including Beaufort/Jasper Comprehensive Health Services, a Title III-funded provider, and private physicians. The Title III provider was first funded in 1998 and operates five local clinics serving Beaufort, Hampton and Jasper Counties. This additional funding for primary case services allowed the consortium to expand support services with Title II funds that had been previously used for primary care.

ACCESS Network employs two case managers, each serving a specific geographic area. One serves approximately 110 clients, the other 65-85. The case managers focus on the assessment of client needs through face-to-face interaction. Most meetings with clients take place off-site, requiring significant

travel on the part of case managers. The agency utilizes support personnel to carry out the benefits management process and complete paper work in order to provide sufficient time for the case managers to meet with clients. Contact with case managers depends on the severity of the client's needs. Approximately 20 percent of the caseload requires intensive contact either daily or once a week. Other clients see their case manager every 6-9 months.

Case managers link clients with primary care providers in the service region. There are no formal linkages between ACCESS Network and these providers. Primary care is available from clinics operated by rural health services, private physicians and non-profit health care providers. Since ACCESS is not formally linked to primary health care providers, case managers play an important role in assuring that clients access care. At intake, clients are asked if they already have a physician that they would like to continue to see and whether they have a source of payment. If the client does not have a physician, a referral is made based on geography and ability to pay. Low-income clients are treated in various local clinics that provide services on a free or sliding-scale basis to eligible clients.

Because the physicians in these clinics see more HIV-infected clients, they often have greater expertise in the treatment of HIV than other physicians in the community. Clients who are not eligible for these clinics (because of income level or they have private insurance) may end up seeing local physicians with less experience in treating HIV or having to drive to Savannah or Charleston to see an infectious disease specialist (anywhere from 50-110 miles one way). ACCESS provides some funds to primary care providers for services such as diagnostic tests, lab work or co-payments that are not covered by other payment sources. The primary care providers invoice ACCESS for these agreed upon services.

In the last eighteen months, ACCESS has been strengthening its ties with primary care providers and there has been greater coordination between physicians and case managers. Physicians and case managers consult about the clients' course of treatment and other factors impacting the client's overall wellbeing. Case managers also serve as a treatment advocate for the client.

As in many rural areas, informal linkages can be very important in obtaining a full range of medical and support services for clients. For example, situated next to ACCESS Network's Hilton Head office is "Volunteers in Medicine," a clinic staffed by retired health professionals who provide free health care. While it was a coincidence that the clinic opened next door to ACCESS Network, it has resulted in a close collaboration between the two agencies and allows case managers to be much more involved in the care of clients receiving treatment at the "Volunteers in Medicine" clinic.

Mr. Speaker, what this report talks about, it kind of looks in depth at two rural States. They chose New Mexico because it had a high incidence of minorities and had a lot of rural cities with small towns in those areas and Hispanics and Indians were in New Mexico. They chose South Carolina again because of the smallness and the rural nature of the State and the high incidence of African Americans. What they found in both of those cases is that there were some challenges in both of those States.

In addition to all the things I talked about earlier, there is a lack of Federal

dollars; there is a lack of public awareness, inadequate housing and unstable home environment. There is just a lack of community understanding, of family support, that they could not, in fact, have the kind of support that would enable people in the South to get it. Also there is a lack of transportation services in those areas, a lack of case management and services and a comprehensive program to respond to AIDS programs, a lack of services to assist people in understanding they need to stay on their drug treatment and have a management system, have a disciplined system where, indeed, they were under those areas, certainly a lack of mental counseling or religious counseling in these areas, and a lack of actually just an appreciation of the disease.

There are issues that indeed affect us in more ways than we would think. But my reason in bringing this, Mr. Speaker, is to have my colleagues to recognize that AIDS is an issue that is affecting the South and is going unnoticed. It is a silent disease killing people. We cannot work on those perceptions that we have had. We need to understand the fact. We really need to look and to see what we can do to curb and certainly the whole issue of sexually transmitted disease and it being a predictor for the likelihood of getting HIV, that ought to be addressed. Only 28 counties in more than 3,000 counties in the country really have any significant cases of sexually transmitted disease, and in North Carolina we certainly have it. There is a relationship. We can fight that. We can fight that only by education and awareness.

The final article I wanted to reference is indeed the impact it is having on women. Again, one of the misperceptions is that this is a disease of white gay men. That could not be further from the truth. As I have said, although men constitute more than female, but the rate at which the growth is going is happening much faster, as I said earlier, again this is North Carolina. And in North Carolina although 68 percent are male, roughly 32 percent are female, that rate is growing faster now for females than for males. And the rate is growing faster for African American females than it is for non-African American females. This article is from the New York Times. Again, Mr. Speaker, I include the article for the RECORD.

[From the New York Times, July 3, 2001]
AIDS EPIDEMIC TAKES TOLL ON BLACK WOMEN
(By Kevin Sack)

GREENWOOD, MISS.—Here is the rural South, the image of AIDS today looks very much like Tyeste W. Roney.

Not a gay white man. Not a crack-addicted prostitute. But a 20-year-old black woman with a gold stud in her nose, an orange bandanna covering her braids, and her nickname, Easha, tattooed on one leg.

In the back of her mind at least, Ms. Roney had known for years that she could contract H.I.V. by having unprotected sex. Her mother had been telling her so since Ms. Roney was 13, when she lost her virginity. But ei-

ther the lesson did not stick, or Ms. Roney did not have the power to negotiate safer sex with older lovers. She says that many of the men she can count as partners did not use condoms.

In February, after enduring 10 days of bleeding, Ms. Roney went to a health clinic. First a nurse surprised her by telling her that she had been pregnant and had miscarried. Then the nurse asked Ms. Roney if she knew she was carrying the virus that causes AIDS.

"I said, 'Get out of here, that can't be so,'" Ms. Roney recalled. "I just broke down and cried. I thought I wasn't going to be here long. Maybe a month."

It is a scene that has become all too familiar for poor black women here in the Mississippi Delta and across the rural south. Even as the AIDS epidemic has subsided elsewhere in the United States, it has taken firm root among women in places like Greenwood, where messages about prevention and protection are often overtaken by the daily struggle to get by.

Researchers say that in many ways the epidemic in the south more closely resembles the situation of the developing world than of the rest of the country. Joblessness, substance abuse, teenage pregnancy, sexually transmitted diseases, inadequate schools, minimal access to health care and entrenched poverty all conspire here to thwart the progress that has been made among other high-risk groups, particularly gay men.

While AIDS rates in the United States remain lower among women than men, women now account for a fourth of all newly diagnosed cases, double the percentage from 10 years ago. That growth has largely been driven by the disproportionate spread of the disease among heterosexual black women, particularly in the South.

For those who contract H.I.V. or AIDS in the rural South, life can become intensely isolated. Because of widespread misunderstandings about the ways H.I.V. is transmitted, the stigma facing those who are infected is often suffocating.

Many women are terrified to tell even their families, and they find their only comfort in the monthly meetings of a support group. One woman here, who lives with her son, is convinced that he would make her eat on paper plates and would keep her away from her grandchildren if he knew of her illness. Ms. Roney, who has informed only her family members, said she lost several neighborhood friends after they saw a health department van pull into her driveway to pick her up for a clinic visit.

Black women, who make up 7 percent of the nation's population, accounted for 16 percent of all new AIDS diagnoses in 1999, a percentage that has grown steadily since the syndrome was first identified 20 years ago. By comparison, black men made up 35 percent, white men 27 percent, Latino men 14 percent, and white and Latino women were each 4 percent.

While the number of new AIDS cases in the United States began to decline in the mid-1990's, the reversal started later for Southern black women, and the drop has been slower.

From 1981 to 1999, 26,522 black women developed AIDS in the 11 states of the former Confederacy. In Mississippi and North Carolina, statistics show that more black women than white men have contracted H.I.V. over the epidemic's course.

Unless a cure is found, the share of AIDS patients who are black and female is likely to rise. The trend is strikingly visible in Southern states with large black populations. Here in Mississippi, 28.5 percent of those reporting new H.I.V. infections in 2000 were black women, up from 13 percent in

1990. In Alabama, the number rose to 31 percent, from 13 percent. In North Carolina, it rose to 27 percent, from 18 percent.

"While the H.I.V. epidemic is also increasingly affecting men in the South and black men, the overall trends for women are distinct," concluded researchers with the Centers for Disease Control and Prevention in a paper published in March in *The Journal of the American Medical Association*. "The H.I.V. epidemic in women initially centered on injection drug-using women in the urban Northeast, but now centers on women with heterosexual risk in the South."

AN EXPLOSIVE INCREASE

In 1997, Dr. Hamza O. Brimah, a Nigerian-born physician who received training in AIDS care in London and New York, opened the Magnolia Medical clinic in a strip mall here in affiliation with the Greenwood Leflore Hospital. Dr. Brimah is the only AIDS specialist in a nine-county area. He started with fewer than 10 AIDS patients. Now he has 185. He assumes he is seeing only a fraction of those who are actually infected.

"In the beginning, I remembered everybody's name," Dr. Brimah said. "Now I have a hard time. Who's this? Who's that? They're coming at me so fast."

Sixty percent of Dr. Brimah's AIDS patients are women and 95 percent are black, in an area where 61 percent of the population is black. Almost all were infected through heterosexual transmission, and a majority, he estimates, came to him with a history of sexually transmitted disease.

Research has shown that people with sexually transmitted diseases like syphilis, gonorrhea and chlamydia have twice to five times the risk of contracting H.I.V., because the diseases cause ulcerations in protective mucous membranes. The South has consistently had the country's highest rates of sexually transmitted diseases. In 1999, for instance, 9 of the 10 states with the highest rates of gonorrhea and syphilis and 7 of the 10 with the highest rates of chlamydia were in the South, according to C.D.C. figures.

Dr. Brimah hears from his patients that H.I.V. is often the least of their worries. "There are issues," he said, "of looking after children, trying to get insurance, the lack of a father in the home, alcohol, drugs. They have so much going on."

Because of that, he said, women rarely seek out H.I.V. testing for themselves or their partners. Many of his patients, like Ms. Roney, learn that they are positive only when they become pregnant.

The other thing Dr. Brimah hears repeatedly from his patients is that they understood before they were infected that H.I.V. could be transmitted heterosexually. Typically, they hold no misconceptions that H.I.V. victimizes only gay white men. And yet, like smokers, speeders and drug users, they place themselves knowingly at risk.

Dr. Brimah told of one patient who dutifully took annual H.I.V. tests for three years, who clearly understood the nature of the virus and who then tested positive in the fourth year. "She was clued up, but she took the risk," he said. "She really couldn't explain it."

The women often struggle to explain their recklessness. They look down at the floor when asked to discuss their sexual behavior. Even those who have had many sexual partners will say they were choosy, that they had known their partners for years, sometimes for a lifetime and that they trusted them. Over and over, they say, they just did not think it could happen to them.

"I just wasn't thinking about no H.I.V., and I wasn't thinking about no AIDS and I wasn't thinking about no pregnancy," Ms. Roney said. "I was just being hardheaded. I don't know any other way to break it down."

Jean, a 44-year-old woman with AIDS who did not want her last name used, said she fell into a fast lifestyle after getting divorced in 1987. She said she might have had 30 to 35 partners over the last 10 years, and that they only occasionally used condoms.

"I guess I just blocked it out of my mind," she said. "I thought I had a good heart so it wouldn't happen to me. I knew it could happen, I guess, but I was just being stupid."

Health workers and researchers who hear these stories say that such high-stakes risk-taking may seem to make no sense, but that it must be viewed within the context of lives defined by fatalism, faith and powerlessness. Often they say, there is little to break the tedium and despondency of life here, and certainly little that provides pleasure, other than sex.

"There's a sense that you don't control your life that much, and if God wants me to have H.I.V. I'll get it," said Kathryn Whetted-Goldstein, an assistant professor of public policy at Duke who has been studying AIDS in Southern states. "All of their life experiences teach them that they have very little control over their future."

Some girls start having sex at extremely young ages, almost always with older men, and find they have little ability to persuade their partners to use condoms.

"Most times I asked them to use one," said Ms. Roney, a ninth-grade dropout, "but you know how guys are. They do their little sweet talk. 'It doesn't feel the same. Let's use one next time.' I just went along with it. I fell into that trap."

POVERTY, DRUGS AND RISK

Often, though not always, drugs and money play a vital role as well. Indeed, Dr. Brimah said the desperate need for money had become an H.I.V. risk factor in the Delta in the same way that needle-sharing was in the cities.

The Mississippi Delta, where the young green cotton crop shares the summer landscape with immense catfish farming ponds, has for years been among the poorest regions in America.

The median income here in Leflore County was \$21,027 in 1997, more than \$7,000 below the state median, which is itself the second lowest in the country. Three of every 10 Leflore residents live below the poverty line. The unemployment rate in April was 7.1 percent (some neighboring counties have broken well into double digits) and the recent closing of several large plants has made work even harder to find than usual.

The poverty is apparent on the rough streets and unpaved alleys of black neighborhoods like Baptisttown and McLaurin, where men and women sweat out steamy nights on the porches of dilapidated shotgun shacks. Just across the Yazoo River lies another world of brick mansions and lovingly tended lawns, where the white people live.

As everywhere, some poor women here make ends meet through prostitution. But the more common practice is a less formalized sex-for-money exchange in which nothing is negotiated up front. Rather, several women and health workers explained, there is an unstated assumption that a woman who engaged in casual sex with a man will be rewarded with a little financial help, perhaps in paying the rent, perhaps in buying groceries. As one woman explained it to Dr. Brimah: "You know how it is with men, doc. No money, no money."

Gina M. Wingood, assistant professor of public health at Emory University who has studied AIDS in rural Alabama, said "It's just trying to make ends meet, day-to-day survival. We sort of see it in terms of prostitution, but they see it as how they have to frame their lives, especially if they have children or elderly parents to care for."

Jean, the 44-year-old AIDS patient, said she regularly operated that way. "Some of them would pay for sex but it wasn't like I was out on the street," she said. "The guy would just give me a little something sometimes. I had an apartment and had bills and I wasn't working."

Jerome E. Winston, a health department worker who tracks the sexual networks of infected people in the Delta, said he had heard complaints from some women about other women who accepted insufficient compensation for their companionship.

"What we had said to us a couple of times by the other girls is that the younger girls are messing up the system because they're giving it away virtually for free," Dr. Winston said. "They don't negotiate anything except for maybe a new CD or a pair of shoes."

Sex is also sometimes exchanged for drugs, particularly crack cocaine, though this seems to be more common in larger towns in the southern part of the state.

Sharyn Janes, a professor of nursing at the University of Southern Mississippi, said she heard horror stories while conducting interviews with people considered at high risk of infection. One man, she said, told her that he once drove a woman out of town when she refused his demand for sex after he gave her crack. He told her that "nobody gets a free ride" and left her to walk home, Ms. Janes said.

TRACING SEXUAL NETWORKS

Because of the breadth and casualness of sexual networks here, an infection can be virtually impossible to track and control.

In the first half of 1999, for instance, health officials untangled a trail left by two H.I.V.-positive men in Greenwood who had had sex with 18 women over a three-year period. Two of the women had had sex with both men. Five were themselves infected with the virus, and they in turn had had sex with 24 other men.

A study of the cluster by the C.D.C. found that half of those interviewed had a history of other sexually transmitted diseases, that some of the H.I.V.-infected women were as young as 13, and that the median age of the infected women was 16, compared with 25 for the infected men.

"The teenager's concept is that this guy is older so he's going to know what he's doing and he will take care of me," said Dr. Shannon L. Hader, a Centers for Disease Control researcher who studied the Greenwood cluster. "The reality is that older men have had more partners and are therefore more likely to have S.T.D.'s."

Clearly, Dr. Hader said, messages about prevention are not getting through. The rural South is politically conservative, and prevention programs in the schools tend to be episodic and focused on abstinence. Parents of students in the Greenwood schools must grant written permission before their children can be taught about condoms. Many local pastors are also reluctant to encourage explicit discussions about sex.

Dr. Hader also found a lack of knowledge about H.I.V. treatment. Five of the seven infected members of the Greenwood cluster had no idea that those with H.I.V. could now live for long periods with the help of antiretroviral drugs. That misconception has made it difficult to get patients into care, where they could also receive information about not spreading the virus.

Those who do seek care have few options. Before Dr. Brimah opened his clinic here, AIDS patients had to travel more than two hours to Jackson or Memphis, a trip that many could not make. Sandra Moore, a 32-year-old Greenwood woman who first learned that she had AIDS in 1990, would sometimes

drive as far as New Orleans for treatment. Ms. Moore had withered to 60 pounds when she first visited Dr. Brimah, and was seemingly weeks away from death. Now on medication, she has increased her weight to 105 pounds and talks of living to see her four young children graduate from high school.

The cost of treatment is also prohibitive for many here. The pills typically prescribed by Dr. Brimah can cost up to \$1,200 a month. Medicaid covers many of the poorest patients, and other state and federal programs help. But the working poor often have trouble qualifying for the programs.

Last year, Dr. Brimah received a three-year, \$1.2 million grant under the Ryan White Care Act, the primary source of federal money for AIDS treatment. He uses the money to pay staff members, to buy equipment, supplies and medication, and to provide transportation to needy patients.

But in general, many Southern states have received a disproportionately small share of Ryan White funds. The money is appropriated to states by a formula based on the number of people living with AIDS in that state. But the growth of the epidemic in the South has been relatively recent, and many of those infected have not progressed from H.I.V. to AIDS. Congress changed the formula last year so that money will eventually be based on H.I.V. counts, but the new system might not take effect for years.

The other factors obstructing treatment, and thus prevention, are denial and stigma. Many infected women here never tell family members and close friends for fear of being shunned and abandoned.

"A lot of people don't understand about it," said Jane Smith, who has only told her pastor and her mother-in-law since learning two years ago that she has AIDS. "I guess they're scared they can catch it from being around people with it, if they cough on them or shake their hands."

One married couple, both infected, said they were open about their status when they lived in New York but had told no one since moving to Mississippi, not even their friends at Narcotics Anonymous meetings. "Everybody would scatter if they knew," said the wife.

Jean has lied to her family members, telling them that she has cancer, and has batted away their questions. Her joy, she said, is her grandchildren, and she is convinced that her son would not let her near them if he knew.

"I want to tell my family," she said, "but I know they're not going to accept it, and I'm just not strong enough right now for them to reject me. It would just send me over the edge."

This article is entitled "AIDS Epidemic Takes Toll on Black Women." Let me just cite a couple of things from it.

It says: "While AIDS rates in the United States remain lower among women than men, women now account for a fourth of all newly diagnosed cases, double the percentage from 10 years ago. That growth has largely been driven by the disproportionate spread of the disease among heterosexual black women, particularly in the South." Again, the South.

"Black women, who make up 7 percent of the Nation's population, accounted for 16 percent of all new AIDS diagnoses in 1999, a percentage that has grown steadily since the syndrome was first identified 20 years ago. By comparison, black men made up 35 percent, white men 27 percent, Latino men 14

percent, and white and Latino women were each 4 percent." Again, in women.

One of the doctors who looked at this says that he hears repeatedly by his patients in New York, and this is a doctor in New York who treats HIV patients, says that his women patients understand clearly, or they say they understand clearly, that they were infected or could be infected with HIV transmitted heterosexually, but nevertheless they go ahead and do it. It is almost like smoking. They say it is like smokers knowing indeed that the smoking is killing them, but they go ahead and do it. It is almost like a death wish. The issue is, is it drugs or is it the need for money? What is driving this kind of reckless behavior?

He says that women often struggle to explain this recklessness. They look down at the floor and they say, I know that what has happened to me is that I was not sure, I didn't protect myself, but yet I knew I should have. I trusted this person. I knew this person. And I just wasn't thinking about getting HIV. These are older women.

Health workers and researchers are struggling to know, How do you make sense of this? How is the relationship between poverty and drugs and risk often a part of this? We just have to find how we address those issues and make sure that as the life and the quality of life in these communities, that people are not walking into their own death trap. Poverty is apparently on rough streets and in the cities, and the exchange of sex for money or the exchange of drug needles that cause that has a strong part to play in it.

"Clearly," Dr. Hader said, "messages about prevention are not getting through." We need to find a way to get those messages through. The rural South is politically conservative, and prevention programs in the schools tend to be episodic at best and more focused on abstinence rather than on protection. Parents of students in many of the schools must have written permission before anything happens. Yet those children are getting the wrong message from other places, many of them becoming pregnant and their children are likewise infected. Most local pastors are reluctant to encourage an explicit or a frank dialogue among their young people so they understand the choices they have. You see, in the South there is indeed, we are fighting not only the lack of infrastructure, we are fighting the issue of attitude.

Mr. Speaker, there is indeed an issue of AIDS across our country. There is an issue of AIDS across this Nation. Certainly there is a severe pandemic in Africa, but there is a creeping disease that is indeed affecting us in the South and in rural communities throughout the United States, particularly in the South. It has the deadly effect of a silent killer. Those of us who know better are charged with the responsibility of waking our citizens up to this horrific disease and making sure that

there are programs of intervention, programs of nurturing, care and counseling, and that our communities indeed will respond to it.

□ 2045

OUTRAGEOUSLY HIGH DRUG PRICES

The SPEAKER pro tempore (Mr. REHBERG). Under the Speaker's announced policy of January 3, 2001, the gentleman from Minnesota (Mr. GUTKNECHT) is recognized for 60 minutes.

Mr. GUTKNECHT. Mr. Speaker, I will later be adding some items to the RECORD.

Mr. Speaker, I rise tonight to talk about an issue that in some respects is a dirty little secret. Yet more and more of us in Washington and more and more seniors around the country know about this dirty little secret. It is about the outrageously high prices that Americans pay for prescription drugs.

Now, I think most Americans are appreciative to the pharmaceutical industry for the miracles they have created over the last number of years. We are all delighted that we have drugs today to treat diseases which just a few years ago were untreatable. We are not unappreciative to what the pharmaceutical industry has done. But the dirty little secret is that the Americans are paying the lion's share, in fact, I might even argue that the Americans are paying the entire share of the research and development costs for these miracle drugs for all the other consumers around the rest of the world.

Several years ago, I talked to some seniors back in Minnesota and they talked to me about going to Canada to buy prescription drugs. But they told me that when they came back after they had their little vials of whatever drug it was, whether it was Claritin or Coumadin or Glucophage or whatever the drug would be, when they would try to reorder that drug from the pharmacy up in Winnipeg or wherever they had bought the drugs in from Canada, when they tried to reorder the drugs and when the drugs came into the United States, they were stopped by the FDA. The FDA then sent a very threatening letter to those seniors saying that if they tried to do this again that, in effect, they could be prosecuted.

Now, if one was a 78-year-old grandmother getting a letter from the Food and Drug Administration in effect saying that she could be prosecuted, that what she is doing is illegal and if she tries to do this again, there are serious consequences, that is a very threatening thing to happen to a senior.

Now, they told me this story. They told me what was happening in their trips, their bus trips to Canada. I have to be very honest. It really did not register with me. In fact, it was not until almost 2 years later when a seemingly unrelated event occurred.